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Mohammadi, Fatemeh; Rakhshan, Mahnaz; Molazem, Zahra; Zareh, Najaf; Gillespie, Mark

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Caregivers' Perception of Dignity in Teenagers with Autism Spectrum Disorder

Abstract

Introduction: Respecting the dignity of patients is one of the main ethical responsibilities of caregivers. However, in many cases, the dignity of patients, especially autistic teenagers is not maintained. The extent to which dignity needs are met for this group within the Iranian care system is difficult to determine as dignity is an abstract concept, and there are few related research studies reported.

Objectives: The objective of the present study is to find out what dignity means for autistic teenagers from the perspective of their caregivers.

Research design: This study uses a qualitative research design. The data was collected through individual, semi-structured interviews and field notes developed during the interviews. In order to analyze the data qualitative conventional content analysis was used.

Participants and research context: Sixteen professional caregivers for autistic teenagers working in public hospitals were recruited based on a targeted sampling method to reach data saturation from February 2016 to July 2017.

Findings: The findings of this study were presented in three main themes, "privacy", "respecting individual identity" and "comprehensive support", and 11 categories.

Ethical consideration: This study's protocol was approved by the Research Ethics Committee of medical universities located in Southeast of Iran and the required ethical principles were followed throughout.

Discussions and conclusion: Based on the findings of the present study from the perspective of caregivers, autistic teenagers need to be cared for and educated in a respectful environment where their privacy is maintained, their individual identities are respected and they receive comprehensive familial, social and financial support. These conditions would maintain the dignity of such teenagers and would result in appropriate behavioral outcomes. Therefore, it is suggested that a cultural, professional and institutional background in which all components of the autistic teenager's dignity are protected and emphasized be provided

Keywords: Dignity, autism, teenager, qualitative research

34 Introduction

35 Maintaining the dignity is one of the fundamental human rights ¹. The term dignity has a lot of
36 meanings, the most important of which are: value, honor, humanity, status, and respect ². The word
37 "dignity" has increasingly become a part of contemporary discussion on health care ³. Because an
38 illness can create a background in which a person's dignity might be violated, all patients need to
39 have their dignity maintained, even under adverse circumstances ^{4,5}. Therefore, maintaining and
40 respecting the patients' dignity is one of the main rights of patients receiving healthcare ⁶, and is
41 also one of the moral responsibilities of caregivers ⁷. The WHO states that all patients are entitled
42 to receive treatment which maintains their dignity ⁸. Therefore, many national and international
43 nursing organizations have considered dignity of patients as one of the basics of caregiving ^{9,10}.

44 Respecting a person's dignity results in an increase in their satisfaction with care provided,
45 improves the relationship between the caregiver and the patient, and also enhances the caregivers'
46 motivations in providing their care ¹¹. However, some studies have mentioned that patients are
47 vulnerable to losing their dignity within caregiving environments ^{12,13} and some of the recent
48 studies have reported a lack of privacy, respect and dignity within such environments ¹⁴.
49 Maintaining patient dignity is a crucial factor in guaranteeing high quality care delivery; therefore,
50 understanding the concept of dignity from the perspectives of the patients or the caregivers makes
51 the treatment process easier and enhances the psychological safety of the patients. Sufficient
52 research is therefore required in order to fully explain the concept ^{12,14}. Based on available studies,
53 dignity is a complicated and multidimensional concept and therefore cannot have a simple
54 definition ¹³. Despite attempts to define this concept and identify its effective elements, the concept
55 of dignity and its related factors remain complicated and unclear ¹⁵. Since maintaining dignity
56 cannot be confirmed without the concept being clearly defined ¹⁶, a need has been recognized to
57 define this concept and to identify the effective elements of dignity among patients with different
58 diseases and disorders ¹³.

59 People with intellectual and developmental disabilities, especially autistic children and teenagers,
60 are more vulnerable to being ignored, abused, and not having their dignity maintained within
61 caregiving environments ^{17,18}. Autism is one of the developmental disorders and according to recent
62 research, this disorder has increased more than 6% throughout the world, creating significant
63 challenges for caregiving organizations ¹⁹.

64 Review of the related literature shows that dignity has been examined in specific categories of
65 patients such as: cardiovascular patients ²⁰, end of life-stage patients ²¹ as well as hospitalized
66 teenagers ²². However, this concept has not been defined for autistic teenagers. Due to their
67 developmental and behavioral disorders, this group of patients are more vulnerable to be ignored
68 and lose their dignity when in formal caregiving environments. Also, the results of the studies on
69 other patients cannot be generalized to patients with intellectual, developmental or behavioral
70 disorders, because the physical environment, organizational culture and the behaviors and
71 perspectives of the care staff can affect dignity ²³. Thus, studies conducted among other patient
72 groups cannot be generalized to autistic teenagers cared for within residential settings. On the
73 other hand, the possibility of examining the concept of dignity from the perspective of autistic
74 teenagers is difficult and ethically concerning, due to their developmental, behavioral and language

75 disabilities. The caregivers of autistic teenagers are the most important and closest people to these
76 teenagers; they spend long periods of time with these teenagers and have the most information
77 about them. Hence, the aim of the present study was to explore the concept of dignity in teenagers
78 with autism spectrum disorder from the perspective of Iranian caregivers, with a view to preserving
79 and improving these teenager's dignity within health systems, and to reflect the necessity of
80 exploring dignity in public health care settings in Iranian society.

81 Qualitative studies can help explain a phenomenon in the cultural context of people's perspectives
82 who deal with a phenomenon for a long time²⁴, so this approach was selected in order to explain
83 caregivers perspectives of dignity among autistic teenagers. It is hoped that the results of this study
84 can help managers and caregivers provide an environment which supports dignity and the rights
85 of teenagers.

86

87 **Objectives**

88 The aim of the study is to explore the concept of dignity among autistic teenagers from the
89 perspective of those caring for them.

90

91 **Methodology**

92 In this research, the authors are trying to explore dignity for looked after autistic teenagers from
93 the perspective of their professional caregivers. Within qualitative research, reality is understood
94 to be individually perceived, meaning a phenomenon can be understood through the commonalities
95 and differences in how those closest to it make sense of it²⁴. Therefore, a qualitative approach with
96 conventional content analysis has been used to investigate this subject. Conventional qualitative
97 content analysis is an appropriate procedure for obtaining reliable and valid results from textual
98 data allowing the creation of new knowledge and innovative understanding of phenomena under
99 investigation. In qualitative content analysis, the raw data is based on inference and interpretations,
100 then it is summarized and placed into categories and themes 25-26.

101 Sixteen caregivers of autistic teenagers were interviewed, all of whom were working the in
102 publicly funded centers providing care for autistic teenagers. These centers being affiliated to
103 medical universities located in Southeast of Iran. Data gathering was performed from February
104 2016 to July 2017. The criterion for inclusion consisted of being Iranian, speaking and
105 understanding Persian, being 24-55 years old, having at least two years of work experience in
106 caregiving centers for autistic teenagers, and the ability to provide appropriate and sufficient data
107 on the subject. The caregivers were selected through purposeful sampling method and were invited
108 to participate in this study.

109 In this study, data collection was conducted through individual interviews; in so doing 16 in-depth
110 semi-structured interviews were conducted with the 16 caregivers. The interviews were carried out
111 face-to-face in quiet environments with the cooperation and willingness of the participants. In
112 addition, field notes were also used allowing collection of what the interviewer sees, feels and
113 experiences, as this helps with analysis of the concept. The individual interviews first started with
114 general questions such as: "what does dignity mean for autistic teenagers? In which situations is

115 the dignity of autistic teenagers at risk?” Based on the answers to these questions, follow-up
116 questions such as “Can you explain more?” “What do you mean?” “Why did you feel so?” were
117 asked. The interviews were carried out based on meeting the main objectives of this study. Also,
118 if necessary, follow-up questions were used in order to increase and clarify information obtained,
119 such as: “Can you explain more? Can you give me an example?” The interviews were recorded
120 and field notes were taken with the permission and awareness of the caregivers. Each interview
121 lasted between 45 and 90 minutes. Immediately after each interview, the interviews were listened
122 to by the first author several times to develop a general understanding and deep insights, and then
123 the interpretations (do you mean interviews?) were transcribed on paper. (Should this read
124 “transcribed verbatim”) Data analysis was carried out after each interview, and later interviews
125 were then scheduled. Interviews continued until the data was saturated. Saturation occurs when
126 there is no new categories emerging and the categories are saturated based on their characteristics
127 and dimensions ²⁷.

128 The data were analyzed simultaneously using the content analysis method; first each text was
129 reviewed for immersion and acquiring insights and deep understanding around the phenomenon
130 under study. Then meaning units were determined based on the objectives and the study questions.
131 Next, important points were extracted as open codes, considering their clear and hidden meaning
132 units. These codes were categorized under broader titles based on their similarities and differences,
133 and the data analysis continued until the themes were extracted ^{25, 27}.

134 In order to ensure trustworthiness Graneheim and Lundman’s criterion were used ²⁸. At the
135 beginning of the study, the researchers bracketed all their prior information and personal beliefs
136 regarding maintaining dignity in the care setting I order to avoid the influence and interference of
137 personal beliefs in the investigation of this phenomenon. To increase the reliability and validity of
138 findings several techniques were employed including combining review of data sources (semi-
139 structured interviews and field notes), prolonged engagement with the data, member checking, and
140 peer checking. To do this, the extracted concepts and themes were submitted to 4 participants and
141 2 peers; who stated that the findings were in line with their understandings and interpretations.
142 Furthermore, the researcher limited the textual reviews in order to reduce bias in collecting,
143 analyzing and coding of the interviews to increase the validity of the date. Finally, Confirmability
144 was acquired through exact recording of participant narratives and detailed reporting of the study
145 to provide the possibility of follow-up for other researchers.

146

147 **Ethical Considerations**

148 The institutional review board of the medical universities located in Southeast of Iran provided
149 ethics approval (approval number: 95-01-08-1168). Also, at the beginning of each interview, the
150 researcher introduced herself and explained the aims of this study, and informed consent was
151 obtained after providing verbal and written explanations. The participants were assured that all
152 information would remain confidential. The researcher created the opportunity for participants to
153 inform the researcher about their withdrawal from the study at any stage of the study and assured
154 them that their lack of participation or withdrawal would not have any consequences for them.

155

156

157

158 **Results**

159 In this study interviews with 16 caregivers of autistic teenagers living in public health centers were
160 carried out. The participants of this study included 10 women and 6 men. The individual
161 characteristics of the participants are presented in Table 1.

162 The three main themes emerging from these interviews were privacy, respecting individual
163 identity, and comprehensive support while 11 categories were extracted from the data. Table 2
164 presents the themes and categories. Dignity for teenagers with autism spectrum disorder is
165 consequently defined as the preservation of privacy; respect for individual identity and the
166 delivery of comprehensive support for these teenagers.

167

168 **A) Privacy**

169 The participants in this study stated that maintaining the sexual, physical, psychological and
170 information privacy of autistic teenagers receiving care in in publicly funded care centers is very
171 important in order to maintain their dignity. therefore, the caregivers respect the patients' privacy
172 and try to maintain it. The privacy theme included four categories: maintaining physical-sexual
173 privacy, maintaining psychological privacy, maintaining information privacy, and respecting the
174 possessive rights of autistic teenagers.

175 The participants in this study reported that due to the patients developmental, behavioral and
176 intellectual disorders, and the high prevalence of reports of physical and sexual abuse of such
177 teenagers, it is essential that they be taken care of by same-sex caregivers.

178 *"Frequently, when delivering care, some parts of the autistic teenagers' bodies, especially*
179 *their sexual organs might be exposed and obviously. based on these teenagers' disorders if the*
180 *caregiver is the same-sex, it would be safer"* (Female, 42 years old).

181 They also said that due to behavioral disorders, such teenagers might show abnormal behaviors
182 which might threaten the physical or sexual privacy of themselves and other people. Therefore,
183 it is essential that autistic teenagers of the same-sex reside together within shared
184 accommodation.

185 *"Sometimes these teenagers show certain behaviors: they take off their clothes in their*
186 *room in the health center; thus, they may threaten the physical and sexual privacy of*
187 *themselves or their roommates. So keeping teenagers of the same sex in one room can*
188 *help support their privacy."* (Male, 38 years old).

189 The caregivers insisted that male teenager should be wearing his pants (trousers) to maintain his sexual
190 and physical privacy. The researcher overheard the following conversation in a center providing care for
191 autistic teenagers:

Caregiver: Put on your pants immediately.

Teenager with aggression: I will not

Caregiver: If you wear pants, you can play with others

He subsequently wears pants with the help of a caregiver

192 Caregivers emphasized that care should be delivered by staff of the same gender as the patient, in order
193 to maintain their sexual and physical privacy. The researcher overheard the following within a center
194 providing care for autistic teenagers:

Supervisor: How many adolescents are hospitalized ?

Caregiver: 6 boys and 4 girls. That means we need 3 male caregivers and 2 female
caregivers.

Supervisor: ok

195 Some of the caregivers also mentioned that it is important to respect the psychological privacy of
196 these teenagers; when teaching appropriate behaviors, we should pay attention to their
197 developmental status and not use their disabilities in a way that destroys their personality or self-
198 esteem.

199 *“Caring and educating these teenagers is difficult. Sometimes the caregivers ignore their*
200 *developmental and physical disorders while educating them, and when these teenagers*
201 *get aggressive and quarrelsome, they will be stigmatized with inappropriate labels; even*
202 *mentioning their disabilities can really ruin their self-esteem” (Female, 30 years old).*

203 In addition, the participants in this study stated that the personal information and the personal
204 lives of these teenagers and especially history of sexual rape or abuse should not be recorded in
205 their files, but should be rather kept confidential by the head nurse or the doctor of the caregiving
206 center.

207 *“Although it is important to keep all the teenagers’ information confidential, it is*
208 *apparent that in our country there is a negative view toward abuse, especially sexual*
209 *assault, and sometimes the file might be studied by people other than the medical staff;*
210 *therefore, it is essential that such information be kept confidential by the person in*
211 *charge” (male, 28 years old).*

212 The participants in this study also said that the caregivers should respect the rights of these
213 teenagers around use of their personal items and accessories.

214 *“Although these teenagers have developmental and behavioral disabilities, the*
215 *caregivers should respect them and understand that they do not have the right to take*
216 *one of the teenagers’ possessions and give it to another teenager without their permission.*

217 *Sometimes the caregivers do this, which results in arguments or fights among teenagers or*
218 *arguments between the teenager and the caregiver” (male, 40 years old).*

219

220 **B) Respecting individual identity**

221 The caregivers who participated in the study stated that it is an ethical principle to respect
222 religious and age identity of autistic teenagers. Also, the caregivers should avoid pity and
223 discrimination in order to maintain the dignity of these teenagers, and should care for such
224 teenagers fairly. This theme included the four categories of respecting age identity and religious
225 identity of autistic children, avoiding pity and discriminatory behaviors.

226 One of the moral principles of nursing care is respecting the age and religious identities of the
227 people receiving care in order to provide appropriate care.

228 *“These are not kids. These teenagers have good physical development and they have*
229 *grown up and we should respect their maturity and age” (Female, 28 years old)*

230 *“These teenagers possess different religious beliefs and I, as a caregiver, respect the*
231 *identity and religious needs of these teenagers and their families, and respect what they*
232 *say even if I dont agree with their beliefs” (Female, 28 years old).*

233 Caregivers also suggested that it is essential to avoid any unnecessary pity in order to promote
234 patient dignity.

235 *“It’s not appropriate to demonstrate unnecessary pity while educating and caring for these*
236 *teenagers, working over sympathetically and being guided by extensive levels of*
237 *unnecessary compassion can destroy their personality and makes us unable to perform our duty*
238 *to educate them appropriately” (male, 38 years old).*

239 In addition, it is vital that the caregivers avoid demonstrating any discrimination when caring for
240 these teenagers and even parents should avoid any discrimination between autistic teenagers
241 and other teenagers in the family and approach them each fairly.

242 *“Sometimes families differentiate between autistic teenagers and their siblings and pay*
243 *less attention to these teenagers and their needs and pay more their attention to their fit*
244 *and well teenager and therefore are discriminating toward their children” (male, 30*
245 *years old).*

246

247 **C) Comprehensive support**

248 Based on the statements of the participants, comprehensive support for autistic teenagers
249 is one of the most important dimensions for creating and promoting dignity for this client
250 group, therefore, it is necessary that these teenagers be provided with comprehensive

251 familial, social and financial support. This theme includes three categories: familial support,
252 financial support and Social awareness support.

253
254 The participants in this study stated that familial support and especially the respect that the
255 parents consider for such teenagers is the most effective factor promoting their dignity.

256 *“The parents of some autistic teenagers are so respectful toward their teenager and*
257 *they are so patient toward the teenager’s aggressive behavior, also important is*
258 *appropriate training and education, which unconsciously makes all caregivers and*
259 *even the relatives of these teenager more likely to behave politely with them. I think*
260 *the support and demonstration of respectful behavior by the family with these*
261 *teenagers has the biggest effect on maintaining dignity of the teenagers by others”*
262 *(female, 41 years old).*

263 Furthermore, the participants reported that if people in general are aware of the persons illness
264 and know that the inappropriate behavior of these teenagers is due to that, they are likely to have
265 more appropriate reactions toward the teenager’s behavior and therefore their dignity will be
266 maintained within that society.

267 *“These teenagers will demonstrate a lot of inappropriate behavior in public and crowded*
268 *places and because of the lack of awareness about their disorder; people would chastise*
269 *autistic teenagers and their caregivers verbally and make them feel uncomfortable,*
270 *alienated and sad. Therefore, if public awareness is increased, people are likely to*
271 *respond moree helpfully in reaction to such inappropriate behavior , maintaining the*
272 *patients dignity” (Female, 32 years old).*

273 The participants also added that caring for autistic teenagers attracts a significant financial burden
274 for families. As a result, there is a lot of ignorance in educating and caring for such teenagers and
275 this will violate the dignity of such teenagers at present and in future; so it is needed to have
276 comprehensive financial support of these teenagers by their families or public organizations in
277 order to promote their dignity.

278 *“Autistic teenagers need to be educated for a long time. Because without extensive*
279 *education, their social skills will not improve and they won’t be able to live independently;*
280 *consequently, their dignity will be damaged. On the other hand, providing prolonged education*
281 *will require large sums of funding. Hence, financial support for these teenagers by*
282 *governmental organizations is needed” (male, 27 years).*

283

284 **Discussion**

285 Human dignity is an important concept in nursing and professional caregiving, and it is one of the
286 fundamental human rights ²⁹. Since teenage patients are more vulnerable, their dignity tends to
287 be more at risk, compared to other groups of patients. Therefore, because of their behavioral and
288 developmental disabilities, can be claimed that dignity of autistic teenagers is more at stake

289 compared to other hospitalized teenagers, the findings of this study emphasizes the importance
290 of maintaining dignity among autistic teenagers. In this study, maintaining dignity of autistic
291 teenagers from the perspectives of caregivers included three main themes: privacy, respecting
292 individual identity, and comprehensive support.

293 The concept of dignity in autistic adolescents has not been explored and defined, Therefore, Due
294 to the lack of relevant studies the findings of this study were discussed with the findings of others
295 studies that were explored the concept of dignity on other patients' population.

296 Privacy is fundamental to human dignity; it is essential to respect the patient's privacy, especially
297 hospitalized teenagers. The present study, based on the perspectives of caregivers for autistic
298 teenagers, revealed that maintaining the physical-sexual, psychological, informational privacy and
299 respecting the possessive rights of teenagers suffering from autism is of great importance. The
300 human dignity is a concept related to the culture, also all caregivers of the present study were
301 Muslims and Iranians and they believe that hospitalized teenagers should also respect the Islamic
302 laws. Furthermore, these caregivers knew that physical-sexual issues were of great importance in
303 Iranian culture and especially rape threatened the personal and familial dignity. Therefore,
304 caregivers tried to keep teenagers of the same sex in one room and also provide professional care
305 by a person of the same sex in order to maintain their dignity. Three related studies also revealed
306 that maintaining physical-sexual privacy among hospitalized adolescents is very important in
307 order to maintain their dignity^{22, 30, 31}. In accordance with the findings of the present study,
308 caregivers should respect the psychological privacy of these teenagers; especially when teaching
309 correct behaviors to these teenagers. A lot of related studies have examined psychological and
310 psychological abuse toward children and teenagers with developmental and intellectual disorders
311 such as autism³²⁻³⁴. In this regards, Reiter's study reports that children and teenagers suffering
312 from developmental and mental disorders are very vulnerable toward stigma, ignorance and
313 psychological abuses³⁵. Caregivers of the present study stated that personal, clinical, and familial
314 information of autistic teenagers should be quite confidential especially the information related
315 to the teenager's sexual abuse should be kept in locked file by head nurse, and should be given
316 to the medical staff only if necessary. One study in Iran on hospitalized teenagers reported that
317 maintaining the information privacy of hospitalized teenagers from their perspective is one of the
318 most important aspects of privacy; these teenagers share their information only with their nurses
319 and avoid revealing their personal information to other people, which reveals the importance of
320 this aspect in maintaining the privacy of patients ²². Respecting the possessive rights of autistic
321 teenagers is another category related to the theme of privacy in the present study. The caregivers
322 in the present study stated that although due to behavioral and developmental disorders the
323 autistic teenagers are unable to participate in caregiving decisions, and such decisions are mainly
324 made by their families and the medical staff, still their possessive rights about their bodies and
325 personal items should be respected and their bodies and personal items should not be touched
326 without their permission. Respecting the possessive rights was referred to as protection of
327 autonomy in other studies; this difference can be due to the developmental-behavioral
328 disabilities of autistic teenagers and the lack of their ability in order to participate in medical
329 decision-making. Therefore, maintaining the physical-sexual, psychological, informational privacy

330 and respecting the possessive rights of these teenagers are necessary for improve the quality of
331 care.

332 Respecting the personal identity is another theme of dignity among autistic teenagers in the
333 present study. Respecting the individual identity in the present study emphasizes respecting the
334 age and religious identity, avoiding pity and discrimination behaviors in order to develop the
335 dignity among autistic teenagers. The participants of this study believed that they needed to
336 respect the age identity and different religious beliefs of autistic teenagers and their families, and
337 should try to meet the religious and spiritual needs of such teenagers. A number of related
338 studies mention the importance of respecting the personal identity by the medical staff as one of
339 the important aspects of ethical care 36, 37, Therefore nurses and other caregivers should respect
340 the patients' national, religious, racial and age differences, and should provide the care without
341 any discrimination ³⁸ 39- 40. Furthermore, the caregivers of this study reported that pity behavior
342 toward these teenagers should be avoided, because such behavior can interfere with the
343 education and caregiving and consequently destroy the self-esteem of these teenagers and
344 threaten the dignity of autistic teenagers. Other studies also stated pity toward patients can have
345 adverse effects on the patients' psychological attitudes and their dignity ⁴¹⁻⁴³. Avoiding
346 discrimination is also another important category related to the theme of respecting personal
347 identity. Participants of this study stated that caregivers should not differentiate between autistic
348 teenagers; even the parents of such children should not differentiate between autistic children
349 and fine children, because it results in threatening the dignity of autistic teenagers. Also avoiding
350 discrimination is a professional value in nursing; caregivers should pay attention not to have
351 discrimination between patients. two other studies also state that there are a lot of evidences
352 that caregivers differentiate between patients and this ethical values are ignored by caregivers
353 ^{44, 45}.

354 Another theme in this study is comprehensive support of autistic teenagers. The caregivers who
355 participated reported the comprehensive support of the autistic teenagers is one of the main
356 needs of such teenagers in order to improve their dignity. These teenagers needed
357 comprehensive familial support in their physical and psychological aspects; social awareness
358 support and financial support. A lot of studies have examined the importance of social and
359 familial support of adolescents; all of them state that such support will enhance the teenager's
360 ability to cope with present situation and improve teenager's behavior ⁴⁶. However, most studies
361 among autistic children and teenagers have examined the importance and effects of familial
362 support and social support of the parents as main caregivers of such children and teenagers ^{47, 48}.
363 Bilgin et al. state that professional and social support will reduce the parents' worries and fears
364 about their autistic children and teenagers ⁴⁹. It is obvious that if the parents of such children and
365 teenagers have the familial and social support, they will be more competent in order to care for
366 their disabled children and teenagers. Also they can better maintain and improve the dignity of
367 teenagers suffering from developmental and intellectual disabilities. Furthermore, the
368 participants of this study added that caring for such children imposes a lot of expenses; thus
369 financial support of public centers is important. Although, many developed countries have
370 centers and communities for the financial support of disabled children and teenagers. But in most

371 developing countries, especially Iran, there are not public centers which support these teenagers
372 and their families financially due to the adverse economic situations.

373 Finally, it can be said that one of the most important care needs of autistic teenagers is to preserve
374 their dignity. The caregivers participating in the present study felt the dignity of these teenagers
375 has been preserved when they were cared in a respectful atmosphere with preservation of their
376 privacy and had also receive the comprehensive familial, social and financial support.

377 **Limitations and suggestions**

378 One of the limitations of the present study was that the caregivers of the autistic teenagers
379 were only from public centers. The selection of the participants from private centers could
380 improve the generalizability of the findings. Another limitation of this study was the collection
381 of data through individual interviews and field notes; making use of other data collection
382 methods could enrich the results of this qualitative study. Therefore, it is suggested that futures
383 studies examine the dignity of autistic teenagers and teenagers with other developmental or
384 behavioral disorders in private centers also in addition to individual interviews, other data
385 collection methods such as observations and focus groups be utilized. Also, more qualitative
386 and quantitative research on larger samples in other places and cultures is needed to explore
387 the concept of dignity in autistic adolescents.

388 **Conclusion**

389 Autistic teenagers are more vulnerable to losing their dignity. Based on the fact that preserving
390 dignity in teenagers can have desirable outcomes, dignity is of great importance, but dignity has
391 not been defined in autistic teenagers. Findings of this study help to define this concept in this grope of
392 patients. According to the results of the present study, providing a supportive atmosphere while
393 respecting the autistic teenager's privacy and paying attention to their individual identity as well
394 as can help to preserve their dignity. In addition, more emphasis on maintaining physical-sexual
395 privacy and respecting the possessive rights of autistic teenagers along with comprehensive
396 support in care helps improve the quality of care and promote of dignity in these teenagers.

397 Since human dignity is an essential value of nursing, especially in autistic adolescents. Therefore it is
398 essential to provide the cultural, professional and organizational environment in which all the aspects of
399 dignity of autistic teenagers are respected. Findings of this study can lead to pay attention to autistic
400 teenager's dignity in nursing education in Iran, and Pediatric nurse specialist respect the dignity of these
401 teenagers and are sensitive to this important issue. In addition the authorities and policy makers of
402 health organizations should examine and use the findings of this study in order to provide appropriate
403 environments regarding the dignity of these teenage in different aspects.

404 **Conflict of interest**

405 No conflict of interest was reported by the authors.

406

407 **Acknowledgment**

408 The present study is a result of the research project issued by medical universities located in
409 Southeast of Iran, therefore the researchers wish to express their gratitude toward the authorities
410 of Nursing and Midwifery Departments, and they also like to further thank the caregivers who
411 participated in this study and other people who helped them carry out this research.

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Table 1. Individual social characteristics of the participants

| Variable |
|------------------------|
| Gender |
| Female |
| Male |
| Education level |
| Diploma of Nursing |
| Bachelor of Nursing |
| Bachelor of Psychology |
| Master of Nursing |
| Master of Psychology |
| Marital status |
| Married |
| Single |

divorced

Age

Min- Max

Mean \pm Sd

Work experience (years)

Min- Max

Mean \pm Sd

Min: Minimum; Max: Maximum; Sd: Standard deviation

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Table 2. Themes and categories extracted from content analysis

| Theme | Category |
|---------------------------------------|---|
| Privacy | Physical-sexual privacy Psychological privacy Informational privacy Possessive privacy |
| Respecting individual identity | Respect for age identity Respect for religious identity Avoiding pity behaviors |

Avoiding
discrimination

Comprehensive support

Familial
support
Social
awareness
support
Financial
support

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